



Abstract

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Project Title: SELF-CARE IN SYMPTOM MANAGEMENT AT THE END OF LIFE

Abstract: *In recent years, there has been growing attention to enhancing patients' end of life care, including a number of national initiatives toward this end. Of the many issues related to end of life care that have been the focus of interest, symptom management has perhaps received the greatest amount of concern because inadequately controlled symptoms add to the suffering of both patients and their family members. It is also widely recognized that distressing symptoms pose a threat to the patients' quality of life. Interestingly, however, the vast majority of research on end of life symptom management has focused on its clinical management. While hospices, the Visiting Nurse Service engage and professional groups (e.g. American College of Physicians) have stressed the importance of preparing patients and their informal caregivers to identify and cope with symptoms and to recognize when professional intervention is indicated, very understudied in end of life research is how patients and their caregiver appraise symptoms and the self-care strategies they use to manage them. Yet, as medical advances extend the final stages of many illnesses and care is more likely to be delivered on an outpatient basis, patients are likely to increasingly try to manage many of their symptoms on their own either as an adjunct to clinical management strategies or in lieu of it, when they perceive the benefits of clinical care as offset by its costs. Self care at the end of life may also be motivated for example, by patients' desire to retain some control over their care, illness and life. Further, the fragmentation of care that often exists at the end of life, the inadequate clinical management of many symptoms, and the often noted tendency for physicians to withdraw from patients when cure is longer the goal, may contribute to the likelihood that patients will feel the need and desire to self manage their symptoms. The proposed study*

will investigate the symptom process and self-care behaviors of 80 older cancer (age 55+) patients with advanced disease and their caregivers (n=60). Specifically we will investigate: 1) the symptom appraisal process; 2) coping responses to common symptoms; 3) the kinds of self-care activities employed; 4) emotional responses to common symptoms.

Thesaurus Terms:

*coping, nursing intervention, patient care management, self care, sign /symptom, terminal patient care
caregiver, emotion, life cycle, quality of life
clinical research, human middle age (35-64), human old age (65+), human subject, interview*

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